



Proudly Affiliated
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Cancer Foundation of
Australia

Payneham

PROSTATE CANCER SUPPORT AND AWARENESS GROUP

NEWSLETTER

Mailing Address

Payneham P.C.S.A.

1 Brixham Rd

St Agnes. 5097

July 2009

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Website www.psapayneham.org

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Next Meeting 7p.m.

Tues 21st July 2009

Payneham R.S.L.,

**360 Payneham Rd,
Payneham**

WE WOULD BE DELIGHTED TO WELCOME YOU ALONG TO OUR MONTHLY MEETINGS, WIVES/PARTNERS OR OTHER FAMILY MEMBERS ARE ALSO VERY WELCOME. (Prostate Cancer also affects wives/partners and family.)

The Payneham Prostate Cancer Support and Awareness Group, provide friendship, support and information to people who have been affected or diagnosed with Prostate Cancer.

WE DO NOT GIVE MEDICAL ADVISE PLEASE TALK TO YOUR HEALTH PROFESSIONAL, WE ALSO DO NOT RECOMMEND TREATMENT MODALITIES MEDICATION OR PHYSICIANS.

REPORT FOR OUR JUNE MEETING

Chair person Phil Davis.

Apologies; Peter & Jenny Woodrow, Garry & Alison Eckermann, David & Adrienne Radbone.

New Members; Keith & Joy Gobbett.

GUEST SPEAKER

DR JEHAN TITUS, UROLOGIST

ERECTILE DYSFUNCTION

TREATMENT OPTIONS

AND MEN'S SEXUAL HEALTH

CHAIR PERSON REPORT

Prior to our June meeting the Payneham RSL had additional electronic equipment installed in there auditorium. This equipment afforded us the opportunity at our June meeting and will also be available at future meetings, to view power point presentations on a large screen, VCR's and DVD's and also listen to CD's. On behalf of the Payneham Prostate Cancer Support and Awareness Group a very big thank you to the Committee of the Payneham RSL for the use of all their facilities and the promotion of our group.

Our monthly newsletters appear on the Payneham RSL website.
www.payneham.rslsa.org.au

They have proposed a two course meal, starting at 5.30p.m. and costing \$10per head with drinks available at the bar. In order that neither the RSL nor our Group experience a loss, it would be contingent on at least 20 people booking and making a non-refundable payment in advance at our monthly meeting, prior to the dinner. Diners would also be required to tidy up and wash up prior to our meeting , which as usual would commence at 7p.m. so that subsequent RSL functions were not inconvenienced. Reg Yorke -Simpkin will further discuss this dining proposal at our July meeting and we look forward for expressions of interest, to ascertain if there are adequate numbers.

Thank you to Ashleigh Moore, of Cancer Voices (SA) for his excellent presentation. His own personal journey has been difficult but through that a large number of other people will benefit. (refer page 3)

TREASURER'S REPORT

Our treasurer Arthur Seager on behalf of our group would like to thank the Prostate Cancer Foundation of Australia for there financial contribution to our group and also a thank you to all our attendees who have made generous 'tin box ' donations. This has assisted in overcoming our earlier cash flow problems, a special thank you to Ken & Joy Gobbett, who donated \$50.00 at our last meeting. These donations have ensured that we are now currently able to meet our expenses and committee members are not out of pocket.

FUTURE MEETINGS

For the remainder of this year we have some excellent speakers who will address some very relevant issues which many men suffer after treatment.

TUESDAY AUG 18th 7.00 P.M.

Dr SAMANTHA PILLAY, UROLOGIST,

WHO WILL SPEAK ABOUT THE WIDE SPREAD PROBLEM OF URINARY INCONTINENCE?

TUESDAY SEPT 15TH 7.00 P.M.

ROSALIE DONHARDT, INCONTINENCE NURSE,

GOOD BLADDER & BOWEL.

DR RIEGER, COLORECTAL SURGEON,

WHO WILL SPEAK IN REGARDTO BOWEL.

TUESDAY OCT 20TH 7.00P.M.

DISCUSSION EVENING. FACILITATED BY

KEVIN O'SHAUGHNESSY.

TUESDAY NOV 17TH 7P.M.

ANNUAL GENERAL MEETING.

ELECTION OF OFFICE BEARERS FOR 2010,

SOCIAL EVENING AND BARBECUE.

PRESENTATION FOR OUR JUNE MEETING

Speaker: Ashleigh Moore, Chair of Cancer Voices South Australia



Ashleigh is a cancer survivor and committed consumer advocate. He was Director at Safework SA (responsible for the State's Occupational Health and Safety and Industrial Relations) when he was diagnosed with a stage 4 head and neck cancer in 2005. Being a strict non-smoker and occasional social drinker, this was a rude awakening. With a wife and two year old daughter at home and limited assistance, Ashleigh coordinated his own care.

Post treatment, Ashleigh's personal commitment to represent the interests, needs and rights of health consumers led to his appointment as the inaugural

chair of Cancer Voices SA.

About Cancer Voices SA www.cancervoicessa.org.au

Cancer Voices SA is representing South Australians whose lives have been affected by cancer, and now has more than 200 members. It is an independent, incorporated, volunteer consumer organization - '**Raising a Voice for those affected by Cancer**' through:

Advocacy (speaking up about problems, 'solution focused', not whinge-ing)

Involvement (engaging with the community, clinicians, government to achieve change)

Awareness (raising awareness about many aspects, across the 'cancer control spectrum' including prevention, treatment, survivorship, palliative care)

Information (reliable, evidence based sources for information)

Cancer Voices South Australia was officially launched by the Minister for Health, the Honourable John Hill in November 2007.



Cancer Voices SA Chair Ashleigh Moore (left) with SA Minister for Health John Hill at official launch of Cancer Voices South Australia on 13 November 2007

Minister Hill spoke of the importance of consumers being involved in their health care through groups such as Cancer Voices and the impact of cancer on everyone.

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CANCER VOICES SA KEY OBJECTIVES ARE:

- **encourage those with experience of cancer** to contribute to all levels of decision making about the disease
- ensure cancer patients, carers and supporters receive the **best possible information and worlds best practice treatment, care and support**
- ensure cancer patients, their carers and supporters are **well represented** to health professionals, government and the public
- Ensure those affected by cancer are treated equally regardless of their **geographical location, social or economic status, age, ethnicity, sexuality, gender, stage or type of cancer**.

We know how important it is to quickly find reliable information about cancer, not only when you are first diagnosed, but as questions arise about your treatment and care throughout the ‘cancer journey’. Cancer Voices have a list of ‘evidence based’ and reliable links on their website at <http://www.cancervoicesa.org.au/website-links.asp> .

Communicating with others in a similar situation is why many people join support groups such as the Prostate Support and Awareness Groups. On-line communication can also be helpful and inspiring, hearing stories from other cancer patients. Ashleigh mentioned that Cancer Voices have links on their website to help you ‘Connect with others’ at <http://www.cancervoicesa.org.au/connect-with-others.asp> . The Cancer Council NSW *Cancer Connections* site is worth checking out.

Cancer Voices has cancer consumer representatives on a number of committees including the SA Safety and Quality in Health Care Council, Statewide Cancer Clinical Network Steering Committee (at the state level) Cancer Australia (at the national level), and we contribute to a national network of Cancer Voices in each state, through [Cancer Voices Australia \(www.cancervoicesaustralia.org.au\)](http://www.cancervoicesaustralia.org.au) . Establishing effective relationship with the Premier, Minister for Health, CEO of the Dept of Health, Heads of Oncology Units in hospitals have also been important steps in progressing changes in cancer treatment and care.

A Cancer Voices cycling team was established to ride in the Tour Down Under Community Challenge in January 2009. The inspiration was provided by Lance Armstrong’s comeback to cycling, to promote cancer awareness. The team is still going, and will ride again in 2010. Arthur Seager is a member of the cycling team, and his participation and encouragement during the training rides helped many to overcome the ‘mental challenge’ of doing a long ride. Going out and ‘getting started’ is often the hardest step.



Cancer Voices is ‘thinking globally, acting locally’ through commitments to the Global Cancer Campaign. Watch their website for updates as this exciting initiative evolves. One component has been holding ‘Cancer Conversations’ with small groups in the community describing their cancer experience. It is vital for us to hear your issues and suggestions. Cancer Voices SA membership is free. Just email info@cancervoicesa.org.au or phone 8291 4343, or go to the website at www.cancervoicesa.org.au . Members receive updates of cancer news, and notification of events and activities. Ashleigh encourages all of us to get involved and help make a difference to cancer care in South Australia. (Pictured; Arthur Seager riding his bike.)

PERSONAL PERSPECTIVE

NORMAN and BETH CHAPMAN

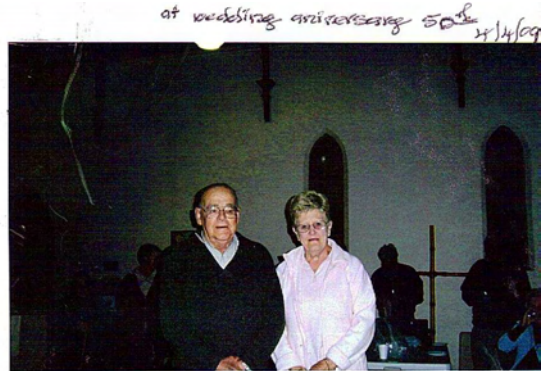
When one listens to the prostate journey of Norm one cannot help but feel a little 'weak at the knees.' When he was diagnosed with Prostate Cancer, his prostate specific antigen (PSA) was 2500, yes that is right 2500. The mysteries of prostate cancer never cease to absolutely amaze me.

Norm and Beth reside in Peterborough which is around 250 kms north of Adelaide. Prior to his retirement in 1998, Norm worked as an electrician at the local power station with a brief stint at Pine Gap. They have two sons who have professional careers, one residing in Adelaide and the other in Melbourne, each during their lives have been diagnosed with a serious illness.

After retiring Norm and Beth enjoyed relatively good health, but in July 2003, Norm just lost his appetite lost weight and was feeling quite tired and lethargic, his sparkle and vigour was on a downward spiral.

As so often happens in relationships, the Director of Home Affairs, his wife Beth, insisted that he visit his local doctor. During the consultation with his Doctor, amongst other procedures the Doctor obtained a sample of his blood. When Norm revisited his Doctor several days later he was informed that his PSA was 2500, the highest reading the Doctor had heard of. The distressing implications of this reading were explained to Norm and he was referred to a hospital in Adelaide for prompt attention.

The following week both Norm and Beth anxiously travelled to Adelaide where a biopsy was conducted as well as a variety of other scans and test. Unfortunately the diagnosis was one where their worst fears were realized, he had metastatic prostate cancer, which was in his bones, with obvious lesions to his ribs and spine. As Norm's prognosis was explained to Beth, she was quite surprised by the frankness of the Doctor and was devastated in regard to Norm's likely outcome. However Norm made a



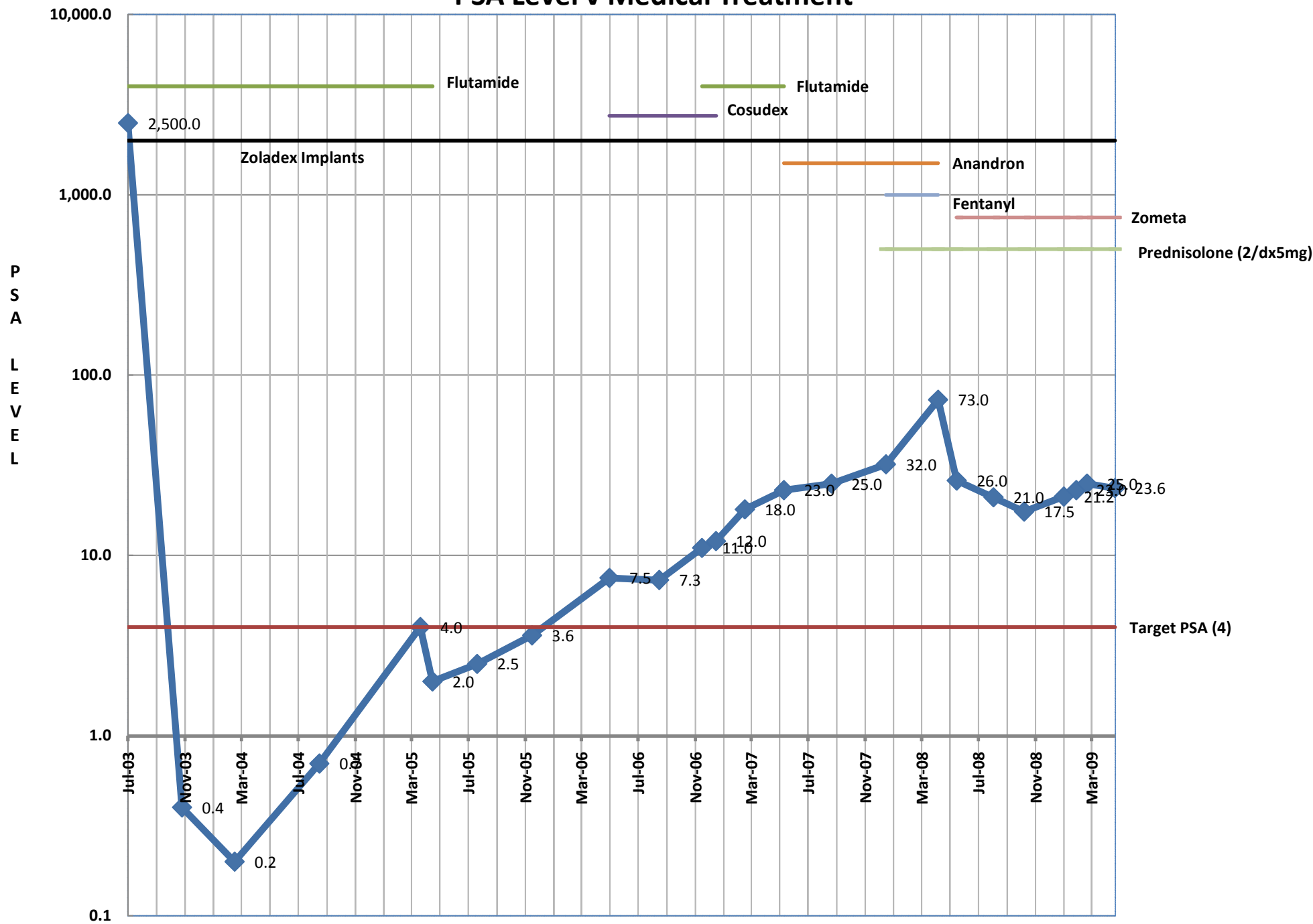
conscious decision to accept his diagnosis and the challenges it would bring. He has steadily developed a determined resolve to remain positive and do everything possible to survive far longer than anyone would expect. Given his daunting diagnosis, I think he is achieving that goal. Some of his positivity and determination along with his continued wellness has assisted in allaying some of the fear and distress initially experienced by Beth.

Norm's treatment commenced with Zoladex and Flutimide and by March 04 his PSA had dropped way down to .2, in March 05 it had climbed to 4, he then ceased taking flutamide and by May 05 his PSA had reduced to 2, then there was a steady climb and by April 06 his PSA was 7.5. He then commenced taking Cosudex and continued with the Zoladex, however his PSA continued to rise and by April 2006 it was 11. At this time he was again prescribed Flutimide until May 07 and at that stage his PSA had continued its upward movement to 23. He then ceased taking the Flutimide and started taking Anadron until April 07, however his PSA at this time was now 73. He was then prescribed Fentanyl followed by Prednisolone and commenced Zometa infusions in June 2008. His last PSA test in April of this year indicated a reading of 23.6.

It is evident that advanced Prostate Cancer, is almost a different disease in each man it affects. The course of the disease is different and the various treatments and medications have differing outcomes. Different therapies have to be tailored by your health professionals for each individual sufferer to achieve the best outcome possible..

NORMAN CHAPMAN

PSA Level v Medical Treatment



NORMAN AND BETH CHAPMAN continued

Considering the variety of treatments and medication in which Norm has been exposed too, his side affects have been quite minimal. He is quite happy with the growth of short hair which has steadily appeared on his head, this has occurred after having a shiny and smooth head for the last 45 year. Another side effect as a result of his exposure to hormone therapy, has been his increased breast development, he is of the opinion that this is a minor inconvenience, when one consider the positive aspects of the treatment.

Currently Norm doesn't have to visit his Oncologist for the next twelve months unless there is a change or some other problem suddenly emerges. He will now be able to have his Zometa infusions at the Peterborough Hospital, so that the seven hour round trip to Adelaide every few weeks will now cease.

There is no Prostate Cancer Support Group in Peterborough, however Norm and Beth enjoy a happy and jovial hour or two, whilst having a cuppa when they attend a local Cancer Support Group for all people diagnosed with any form of cancer, their carers and any other interested person. They often have a guest speaker who speaks about anything, except cancer.

For Norm and Beth there is life after a diagnosis of cancer, they both enjoy the company and a laugh with family and friends, humour is great medicine for them. Norm spends a lot of time in his garden, more looking than actually doing anything and they both enjoy singing in the local Peterborough, 'Sing Australian,' Choir, Norm is unable to read music and does not have the singing ability of Frank Sinatra or Dean Martin but perhaps he has the humour to rival them.

Norm despite his prognosis emphasised he preferred to think of all the doors that his cancer has opened and all the funny bits along the way. To live each day with joy and laughter, be thankful for what you have, rather than pinning for what you want. He continues to be optimistic and positive in regard to his future

Beth and Norm recently celebrated their 50th wedding anniversary, congratulation to both of you and on behalf of the Payneham Prostate Support and Awareness Group, my very best wish for your future together.

"Our lives begin to end the day that we become silent about things that matter."

Martin Luther King

VALE ERIC (TREVOR) HUNT.

It is with sadness that we learn of the recent passing of Eric (Trevor) Hunt as a result of prostate cancer.

For many years although seriously ill, Trevor along with his wife Coralie, assisted many families who experienced a diagnosis of prostate cancer. Trevor through the Action Group continued raising the awareness of prostate cancer throughout South Australia and produced an excellent newsletter, which assisted with the education process about prostate cancer. He was also a founding member of the national support and advocacy committee.

In appreciation of his contribution, he was awarded the Max Gardner Award and the Premier Certificate of Appreciation.

Robyn and I personally, along with the members of the Payneham PSA Group extend our deepest sympathy to Coralie and family.

Trevor's wisdom, passion and contribution will be greatly missed.

Mayo Clinic (U.S.A.) announces dramatic results in advanced prostate trial.

Mayo Clinic Press Release; 19th of June 2009.

Patients whose prostate cancer had been considered inoperable are now cancer free, thanks in part to an experimental drug therapy that was used in combination with standardized hormone treatment and radiation therapy. The men were participating in a clinical trial of an immunotherapeutic agent called MDX-010 or **ipilimumab**. In these two cases, physicians say the approach initiated the death of a majority of cancer cells and caused the tumours to shrink dramatically, allowing surgery. In both cases, the aggressive tumours had grown well beyond the prostate into the abdominal areas.

“The goal of the study was to see if we could modestly improve treatment for advanced prostate cancer,” said Eugene Kwon, MD., Mayo Clinic urologist and leader of the clinical trial. “The candidates for this study were people who didn’t have a lot of other options. However, we were startled to see responses that far exceeded any of our expectations,”

The patients first received hormone therapy, (androgen ablation) researches then introduced a single dose of ipilimumab, which builds on the anti-tumour action of the hormone and

causes a much larger immune response, resulting in massive death of the tumour cells. Both men experienced consistent drops in their prostate specific antigen (PSA) counts over the following weeks until both were deemed eligible for surgery. Then during surgery came a greater surprise.

“The tumours had shrunk dramatically,” said Michael Blute, MD. Mayo urologist, co-investigator and surgeon, who operated on both men, “I had never seen anything like this before. I had a hard time finding the cancer. At one point the pathologist (who was working during surgery) asked if we were sending him samples from the same patient.”

One patient underwent radiation therapy after surgery and both have resumed their regular lives. **Further research is being planned to understand more** about the mechanisms of the antibody and how best to use the approach in practice.

“This is one of the holy grails of prostate cancer research.” Says, Dr Kwan; “We’ve been looking for this for years.”

The research was supported by the Department of Defence, The Richard M Schulze Family Foundation, the Mayo Clinic Cancer Centre and the Mayo Clinic Centre for Translational Science Activities. Mendarex, Inc provided the study drug.

Library News

Librarian Kathie Seager advises our Library is steadily growing, and books are available for loan at each meeting.

QUEEN'S BIRTHDAY HONOURS.

We Congratulate Dr Carole Pinnock, who is a Principal Research Scientist in the Urology Unit at the Repatriation Hospital at Daw Park, who received an AM (Member in the General Division) for service to medicine, particularly urological research and to men's health through the development of support programs for people with prostate cancer. Dr Pinnock, also of the Australian Prostate Cancer Coalition, is principal author of the consumer guidelines for advanced prostate cancer and is obtaining input from a working party that represents a broad range of health care and Prostate Cancer Foundation of Australia consumer involvement, in different aspects of the prostate cancer journey.

The Payneham R.S.L. is located on the southern side of Payneham Rd, about 100 metres east of the intersection of Payneham Rd and Portrush Rd. a car park is available on the eastern side of the hall, enter the eastern side door of the R.S.L. from the car park.

Membership to join the Payneham Prostate Cancer Support and Awareness Group is free as the group is funded in part by the Prostate Cancer Foundation of Australia, however we do welcome and depend on donation to fund the remainder of our expenses.

Supper (Tea Coffee and Biscuits) is provided free of charge at each meeting and the bar at the R.S.L. is open prior to and after each meeting.

For further information or a chat please call Phil Davis, Ph82632217, Peter Woodrow, 82635556 or Arthur Seager, Ph 82894180.

**A SPECIAL THANK YOU TO THE COMMITTEE OF THE PAYNEHAM
R.S.L.**
